



# Case managers for rare diseases: Roles and training outlines

An outcome of the INNOVCare Workshop on Advancing Holistic  
& Innovative Care for Rare Diseases and Complex Conditions in  
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## 1. BACKGROUND AND METHODOLOGY

In April 2016 the Commission Expert Group on Rare Diseases unanimously adopted [recommendations](#) to support the incorporation of rare diseases into social services and policies, including the recommendation for Member States to promote measures that facilitate multidisciplinary, holistic, continuous, person-centred and participative care provision to people living with rare diseases.

The INNOVCare project aims to bridge the gap in the co-ordination between medical, social and support services in the European Union Member States. In this scope, the [NoRo Resource Centre](#) in Romania is carrying out a pilot project on case management for rare diseases.

Throughout the INNOVCare project, representatives of national and regional competent authorities ([INNOVCare Advisory Group](#)), social services, patient representatives, healthcare providers, social workers and academics meet to discuss ways to implement holistic care for rare diseases and complex conditions.

The following proposal for the outline of the role and training of case managers for rare diseases was developed based on:

- The first European survey on the impact of rare diseases on daily life, ["Juggling care and daily life: The balancing act of the rare disease community"](#): answered by 3.000 people with a rare disease and carers;
- Project experience from:
  - INNOVCare pilot project of case management, Romania;
  - Pilot scheme TCC Valais carried out by ProRaris, Switzerland;
- Consensus-building sessions at multistakeholder workshops:
  - ["Improving Integrated Care for People Living with a Rare Disease & Complex Conditions"](#) in Sweden, September 2016 (45 participants from 20 countries);
  - ["Advancing Holistic & Innovative Care for Rare Diseases and Complex Conditions"](#) in Romania, June 2017 (46 participants from 18 countries).

## 2. GENERAL OUTLINE OF THE ROLE OF A CASE MANAGER FOR RARE DISEASES

1. Single and stable point of contact;
2. Listen, inform, support and empower patients and families:
  - Provide knowledge/tools for patients to be able to acknowledge their personal situation;
  - Develop individual long-term care and life plan with person with a rare disease and their family;
  - Inform about existing resources (services, rights, compensations);
  - Encourage and support health literacy, self-care, family resilience and compliance to treatments;
  - Develop working methods that support empowerment of patients and families;
3. Assess/monitor needs & be an observatory of those needs;
4. Holistic and patient-centred care planning and care co-ordination:
  - Identify resources available in the territory - services and support;
  - Refer to available resources and speed up access to services and support;
  - Simplify care pathways & support navigation for patients/families and professionals;

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- Support transition periods & deliver continuous structured support to prevent care ruptures and facilitate independent life;
  - Facilitate work of care providers as a multidisciplinary team: create the link/facilitate coordination between services & professionals; mobilise them to build networks;
5. Hub of information and knowledge;
  6. Inform, support, train and empower professionals involved in care provision;
  7. Facilitating networks of service providers;
  8. Prevention of avoidable high risk situations:
    - Identify most vulnerable cases at risk of serious situations and possible prevention measures;
    - Follow up with patient to avoid over-use of health services for lack of information.

### 3. EXAMPLE OF ACTIVITIES OF A CASE MANAGER

An example from the [INNOVCare pilot project](#) at NoRo, Romania:

1. Provide information about disease;
2. Inform about rights as a patient;
3. Support self-management of care;
4. Improve communication skills;
5. Gather and share knowledge of available services;
6. Foster disease-related peer-to-peer learning;
7. Foster understanding and acceptance in community;
8. Support coordination of care among stakeholders.

An additional example for case management is the pilot scheme TCC Valais, that was carried out by ProRaris, Switzerland: <http://bit.ly/TTCValais>.

### 4. OUTLINE OF MODULES FOR TRAINING OF CASE MANAGERS FOR RARE DISEASES

1. Introduction
  - Introduction to the service and project setting
  - Vision, definition of case management
  - Skills, qualification and abilities for case managers
  - Case studies – other national/project experiences
2. Rare diseases - general information
  - Testimonials from patients and families
  - Access to diagnosis/diagnosis tools
  - Assessment of the degree of disability
  - Access to education
  - Access to employment
  - Social inclusion
3. Case management and communication
  - Efficient communication: personal and virtual communication
  - Developing communication skills
  - Conflict solving & networking

4. Resilience

- General information on family resilience
- Empowering patients and families
- Announcement of diagnosis and impact on family
- Personal development and self-esteem

5. Development and coordination

- Description, definition and possibilities
- Legislation - rights and obligations, health and social welfare and insurance system
- Finding the right information
- Available Services
- Organising trainings for professionals

6. Work methodology

- Methodology of case management for people with rare diseases and their families
- Ethics and data protection
- Tools used in case management for rare diseases
- Supervision of case managers

7. Fundraising

Skills for case managers

- Positive approach
- Effective communication and negotiation skills
- Ability to perform ongoing evaluation
- Critical thinking and analysis
- Ability to plan and organise
- Ability to promote client autonomy and self-determination